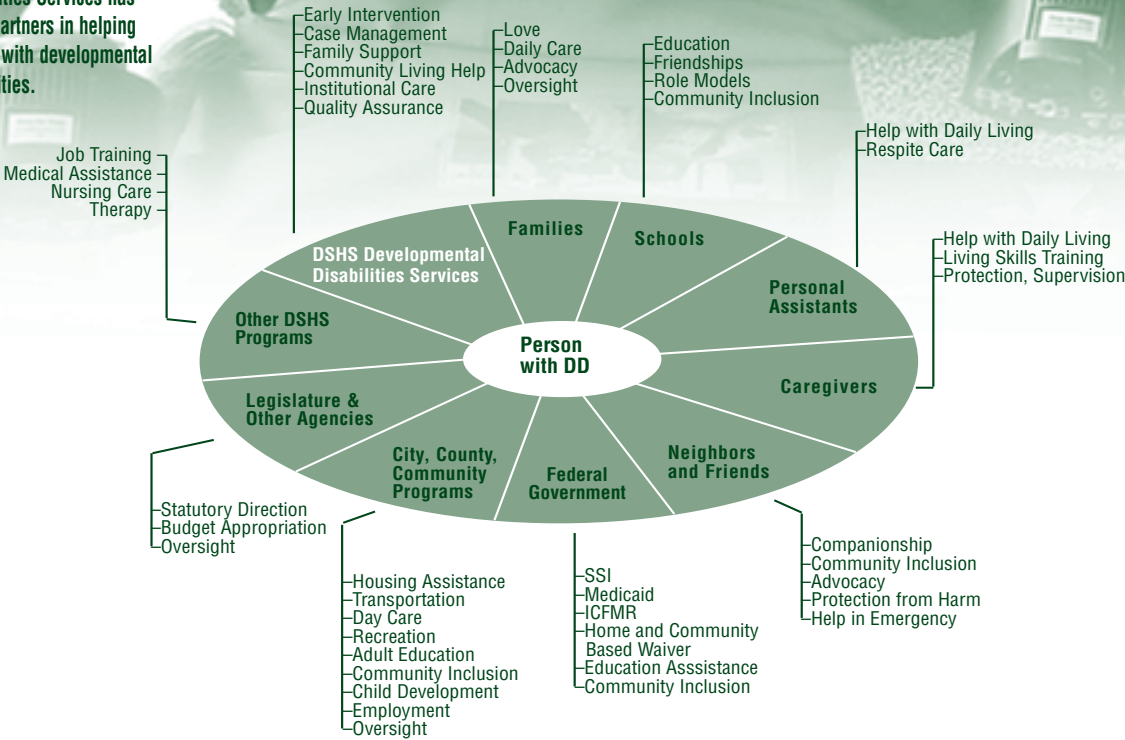




Photo courtesy Developmental Disabilities Services

The DSHS Developmental Disabilities Services has many partners in helping people with developmental disabilities.



Developmental Disabilities Services

Most people who have developmental disabilities can run, laugh, fly a kite, and enjoy a picnic. As adults, many hold jobs, live in their own houses or apartments, go to movies, and visit with their neighbors. But even people with mild developmental disabilities are vulnerable, because they learn more slowly, are easier to deceive, and less likely to grasp many of the complexities of modern life. They might not be able to balance a checkbook, drive a car, compare prices at the grocery store, follow a recipe, find a job on their own, or (like a lot of us) program a VCR.

People with more severe developmental disabilities may never be able to learn to speak (or to speak clearly), to walk, or to dress themselves.

Developmental disabilities include mental retardation and several conditions that can (but don't always) produce similar results: cerebral palsy, epilepsy, and autism. Other neurological disorders similar to mental retardation are also considered developmental disabilities.

One of the defining characteristics of developmental disabilities is that they last for life. There is no cure for mental retardation, autism, cerebral palsy, or other neurological conditions that may impair intellectual functioning.

This means that people with developmental disabilities are likely to need special supports through all the stages of life: as infants and toddlers, as children, adolescents, adults, and as senior citizens.

Developmental disabilities are different than mental illnesses or injuries from which people may recover. However, Intelligence Quotient (IQ) isn't the only measure of disability. Some people with autism or cerebral palsy, for instance, may have normal to high IQs, but have great difficulty expressing themselves or communicating with others, and may also have physical disabilities so severe that they require 24-hour support.

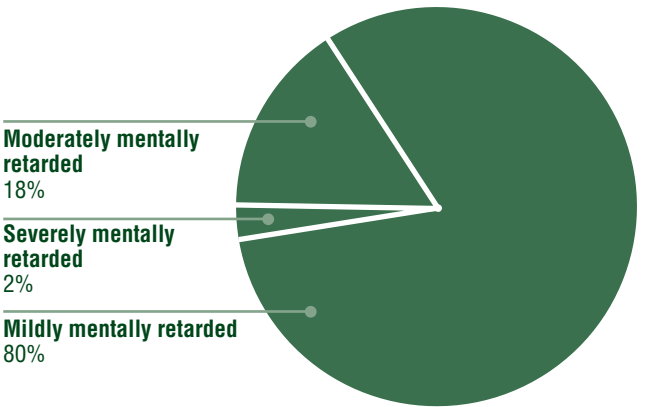
Some people who are mildly mentally retarded are separated by just a few IQ points from people who are not considered disabled. Generally speaking, people are considered to have a developmental disability if their IQ is below 70. A person with an IQ even slightly above 70 is not considered disabled. (One hundred is the median IQ; this means that half us are below 100 and half of us are above.)

Residents Receiving DSHS Services: SFY 2000

DSHS Services by Program	Total Clients
Developmental Disabilities Services	33,200
Personal Care Services	9,180
Voluntary Placement-Children	725
Case Management	31,195
Residential Habilitation Centers (RHC)	1,330
Community Residential Services	5,285
County Contracted Services	9,750
Family Support Services	6,095
Professional Support Services	4,120
Miscellaneous	485

Source: The DSHS Client Data Base, Research and Data Analysis FY 2000

Most people with developmental disabilities are mildly mentally retarded



About 80 percent of people with developmental disabilities are mildly mentally retarded. Of the remaining 20 percent, about 18 percent have disabilities classified as “moderate,” and about two percent have disabilities classified as “severe” or “profound.” Some people with developmental disabilities also have related health conditions that make them medically fragile.

Each state has its own legal definition of developmental disability, and these definitions are the basis for deciding who is eligible for government help and support. Washington state’s definition is spelled out in the Washington Administrative Code (WAC) 388-825-030.

There is no perfect definition; each state struggles over questions about who is developmentally disabled and who is not. Adults who sustain brain injuries often have many of the same conditions as people with developmental disabilities, but in Washington state, they are not defined as people with developmental disabilities. Children born with problems that result from their mother’s drug or alcohol consumption are also not included in our state’s definition of developmental disability, but if they have developmental delays, they are eligible for early intervention services when they are infants and toddlers.

Developmental disabilities can occur in any family

There is no way to predict who will have children with developmental disabilities. President John F. Kennedy had a sister with mental retardation. Other families that are highly educated, successful, and prosperous have children with developmental disabilities, too. There are people with developmental disabilities from every walk of life - rich and poor, urban and rural, and among people of every race and nationality.

Most people with developmental disabilities were born with them. A few become disabled as the result of an accident (such as a difficult birth or a near-drowning) that causes the brain to be deprived of oxygen for more than

a few minutes. Babies that are born prematurely are also more likely to have developmental disabilities.

Some developmental disabilities, such as Down Syndrome, can be identified before a child is born. Others don’t become apparent until parents observe that their child is not developing skills expected at his or her age.

Sometimes babies and very young children are included in early intervention programs because it’s hard to tell if they have developmental disabilities, or if they simply need more stimulation to develop properly, or if they have a developmental delay caused by a medical problem such as impaired hearing or sight. Early intervention programs help families sort out these differences and get their children the help they need. About one third of the

infants and toddlers who receive early intervention services do catch up with their peers, and don't need further special services after age three.

Developmental disabilities are not considered medical conditions. But like everyone else, people with developmental disabilities have benefited from medical advances that help all of us live longer, healthier lives. The development of antibiotics and better treatments for heart defects, for instance, have been of special significance to people with Down Syndrome, who used to succumb to congenital heart ailments or childhood infections. In 1910, their life expectancy was 9 or 10 years; now people with Down Syndrome live to an average of 55 years or more. People with cerebral palsy have benefited from medical and technological advances that help them with communication and mobility.

How our society's ideas about people with developmental disabilities are changing

In 1886, the territorial government of Washington opened a school for "defective and feeble-minded youth." This marked the beginning of our state's long history of creating institutions to house people with developmental disabilities.

During many of those years, parents were pressured to give custody of their children with developmental disabilities to the state. Some parents were even advised not to take their babies home from the hospital, but to send them directly to an institution,

where they were expected to remain for their entire lives.

Many people genuinely believed that isolating people with developmental disabilities in institutions was best for them, because they would be protected from ridicule and abuse in the community or neglect by their families.

During the long era when institutional care was the only socially acceptable option, families expressed their love and loyalty to their children by organizing the Children's Benevolent League in 1935. The League pressed for more and better institutional care. Later, the League became the Association for Retarded Children/Citizens (ARC), and has continued to work for improvements in the way our society treats people with developmental disabilities.

Now, because the term "retarded" has been so often used as an insult, the Arc has dropped the word from its name, and is known simply as "The Arc."

By the late 1960s, the population of Washington's institutions for people with developmental disabilities peaked at 4,200. But large institutions tend to have large problems, and Washington's were no exception. Over the years, they had been prone to periodic scandals about mismanagement, abuse of residents, and inadequate care. These concerns helped to fuel a growing movement for community-based living arrangements for people with developmental disabilities.

At the same time, the civil rights movement inspired people with

disabilities and their families to think differently about themselves and their potential. Many concluded that their biggest obstacle to personal fulfillment and happiness was not their disability, but the prejudice and discrimination they faced.

Since then, people with developmental disabilities, their families, and other advocates have worked to enlarge the opportunities and choices available to them by changing our society's beliefs and values. They have insisted, for instance, that they are "people with developmental disabilities" - that is, that they are people first, and that they should be defined by who they are as individuals rather than by the fact that they have a disability.

They have also rejected the "medical model" of regarding developmental disabilities as an incurable disease to be "treated" rather than a condition that is simply a part of life. The medical model simply didn't work. And it assigned a superior, "expert" status to doctors and other professionals, rather than acknowledging that it is people with developmental disabilities and their families who best understand what they need and want.

This change in thinking may sound simple and straightforward, but it has huge and complicated implications - many of which are unresolved. Some people with developmental disabilities and their advocates, for example, now

question the wisdom of events like the Special Olympics that segregate people with disabilities from others. They don't want to be regarded as "special," but simply as ordinary. Others contend that the enemy of people with developmental disabilities is not segregation, but isolation - and therefore they continue to support some living, schooling, working and recreational arrangements that provide ways for people with developmental disabilities to work and socialize with each other.

There is a strong consensus, however, that everyone should be able to choose how they will live, be accepted by others as individuals, and be included in the activities of their communities regardless of their differences.

We are still in the midst of a long struggle for our society to fully accept and include people with physical disabilities. It promises to be an even longer and more difficult struggle to accept and include people with developmental disabilities, because we have such a long history of discounting and ridiculing people who have them.

That's why people with developmental disabilities and their advocates work so hard to remind the rest of us that people with developmental disabilities are people - and that the value of a human life should never be measured in IQ points.

There is no correlation between intelligence and wisdom, or between intelligence and virtue.

If there were, people without developmental disabilities would not harbor prejudice towards people who have them.

Today's system of supports for people with developmental disabilities

Since 1886, when the Territorial Government of Washington opened the first institution for children with developmental disabilities, our society has acknowledged that government has a responsibility to help them, and to help their families care for them. Today, that responsibility has evolved into a complex web of services and supports funded by federal, state and local governments, and provided mostly by family members, public schools, individual caregivers and private and nonprofit agencies. These services comprise a system that helps people throughout their lives.

Four trends drive a growing demand for services: continuing increases in life expectancy, growth in the number of parents becoming too elderly to care for their adult children, medical advances that save the lives of premature infants, and population growth. The number of people who are eligible for services is growing at six percent per year.

This rate of increase is difficult for citizens and policymakers to grasp, because most human service programs serve people whose needs are temporary. People who are unemployed, injured, or in need of substance abuse treatment complete these

programs and leave the caseload. Elderly people who rely on the human services system eventually pass away. This constant turnover in clientele means that more people can be served. But in the world of people with developmental disabilities, some level of support - ranging from minimal to intensive - is needed from infancy through old age.

The result is that demand has outstripped supply - and so the services people need aren't always available when they need them. Over 5,000 families are on a waiting list for the Family Support Program, and although emergency needs are addressed promptly, the average wait is about 18 months. A study of the unmet housing, employment, personal support and therapy needs of people with developmental disabilities published in 1999 found that the state Developmental Disabilities Services (DDS) was fully serving the needs of only 62 percent of its caseload.

The State Legislature has significantly increased funding for services since that study was published, but even those increases have not been able to fully address the unmet needs, or to slow the growth of the Family Support waiting list. That's partly because much of the added funding has gone into costly community protection programs that house and supervise people with developmental disabilities who have committed violent crimes, but may not be competent to stand trial.

Demographers estimate that there are over 100,000 people in

Washington state with developmental disabilities, but DDS's caseload is less than 35,000. There are a variety of reasons for this disparity. Some families may not ask for help because they don't know it is available, or because of cultural or language barriers. Others may simply not need services during the years when their children are served by public schools.

The highest needs for help come during times of transition - when a developmental delay is first identified, when a young person graduates from high school, when a young adult wants to move out of his or her parents' home, when parents become elderly or ill, or when family support systems break down for some other reason.

The major elements of Washington state's system of supports for people with developmental disabilities are:

Case Management Services help people with developmental disabilities and their families find out what they are eligible for, make plans, arrange for services, find local resources, and change services and supports when necessary. Case managers also monitor the delivery of services that may come from a wide variety of agencies and providers.

In spite of recent funding increases, Washington state still has more clients per case manager than any other state. This means that services to many people aren't monitored very frequently, and that many people rarely see their case manager. It also means that case

managers are overworked, and that many "burn out" and take other jobs.

Early Intervention with Infants and Toddlers is provided to families who have babies or young children who experience a developmental delay, even if the delay is not caused by a permanent disability. Early intervention can help identify the cause of a delay, connect parents with special help and support, and ensure that children get off to a good start in life.

Family Support Services help people find and pay for respite care, therapy, special equipment, and participation in community activities that are needed because of a child's developmental disability.

Medicaid Personal Care provides funding to help both adults and children get the help they need in their own home for basic tasks such as dressing, toileting, bathing, meal preparation, laundry and supervision.

Education for children with developmental disabilities is provided by public schools under the terms of a 1975 federal law called the Individuals with Disabilities Education Act (IDEA). This law requires public schools to educate all children with developmental and/or functional disabilities from age 3 to 21. Some school districts also provide educational services to infants and toddlers.

The federal law is actually based on a similar law passed by the Washington State Legislature in 1972. Washington state has the distinction of being the first in the nation to pass such a law.

The advent of free and appropriate public education for children with developmental disabilities was nothing short of revolutionary. Nearly a century before, Washington's state constitution declared that "it is the paramount duty of the state to make ample provision for the education of all children residing within its borders." But in practice, children with both physical and developmental disabilities had been routinely excluded by school systems that simply weren't designed to meet their needs. This new law required significant change in the design of public school systems, and in the training of teachers. It also opened a whole new world to children with disabilities and their families.

Children with developmental disabilities benefit from the role models provided by their classmates. The daily social interaction of public school helps them achieve higher levels of skill in speech, social interaction, and academics, and fuels higher aspirations for meaningful and productive adult lives.

Recent advances in research and teaching have shown that many people with developmental disabilities can learn more than we used to think they could.

Integrating children with disabilities into our public schools also made it possible for other children get to know people with developmental disabilities. Many

Learning for life



Photo by Della Jordan

Doctors said Jeanine Ervin, who has moderate mental retardation, couldn't learn after she became 21 and her special education classes ended. But she is a valued employee of Milgard Windows in Tacoma. And she bowls, watches television and cares for a small Shih Tzu named Boy Dog. In fact, her mother says she has found a pleasant and happy life for herself.

Read Jeanine's story on Facing the Future Profiles, located at <http://www.wa.gov/dshs/FacingtheFuture/NewsProfiles>

people believe that this has significantly reduced prejudice, and that those who have attended school since this law was passed are much more likely to accept and include people with all kinds of disabilities.

Making public education a right for all children also changed the world for people with disabilities in another way. By defining equal access to education as an

entitlement, it raised the expectation that government services should help level the playing field for people with disabilities at all stages of their lives.

Employment and Training

Programs for new high school graduates and for other adults are provided by county governments, private agencies, and the Division of Vocational Rehabilitation. People with developmental disabilities work at Microsoft, Boeing, Nordstrom, Physio-Control, and many other companies. Many also work for state, federal and local government agencies. Some people with developmental disabilities work in sheltered workshops or in special groups in private sector firms, but more and more are succeeding at ordinary jobs with minimal special support.

Washington state is nationally known for the excellence of its employment programs for people with developmental disabilities.

Residential Placement Services help people with developmental disabilities choose where to live, and with whom.

Today only four percent of people with developmental disabilities live in state institutions, and most of them are long-time residents. New admissions to state institutions are very rare, and each year, more people leave state institutions to live in the community.

Since about 1970, there has been a sustained effort to help people move out of state institutions and into community settings. Many families report dramatic improvements in

people's abilities, their behavior, and their happiness when they leave institutions and are able to lead more typical lives.

Eight states and the District of Columbia have closed their institutions completely. But in Washington state, some parents feel that their adult children are more secure in a state institution, which they regard as more stable and predictable than a community placement might be. Others believe that their children's disabilities are too severe to allow them to live in a community setting - or, to put it another way, that the community has failed to provide good, safe places for people with severe or profound disabilities. And still others think that institutions should be kept open to serve people who have been there for so long that a change in lifestyle would be hard for them.

Naturally, the people who work in institutions and their unions also support keeping them open. They believe that the expertise of experienced institution staff is special benefit to the people they serve.

A 1999 U. S. Supreme Court decree called the Olmstead Decision requires that people living in institutions be given the choice to live in the community if professionals believe they can live independently or in a supported community setting, and forbids states to keep people on lengthy waiting lists for community placement. To comply with this decision, the Washington Legislature allocates funds specifically for the

purpose of helping people in institutions move into community placements.

A wide range of community-based living arrangements are available. Many people live at home with their families. Others live in their own rented apartments or houses, either alone or with roommates. The Tenant Support Program helps people who live on their own and need some assistance with shopping, managing money, cooking, or other activities. Some people own their own homes or condominiums. There is also an Intensive Tenant Support Program for people who need daily or around-the-clock support. In addition, people with developmental disabilities may live in adult family homes, group homes or in intermediate care facilities.

Unfortunately, in many instances people's options are limited if they live in a rural area where provid-

ers are scarce, or if there aren't openings in the group home or adult family home of their choice, or if their case manager is unable to devote the time needed to help them make necessary arrangements.

Health care, mental health care, and other services

Like everyone else, people with developmental disabilities sometimes need mental health care, medical care, dental care, substance abuse treatment, and other services that are provided or paid for by other human service agencies. Sometimes these needs are problematic. For instance, most mental health practitioners are not trained to work with people with developmental disabilities, and may not be able to recognize what behaviors are the result of a person's disability, and which are the result of a

mental illness. People with developmental disabilities may also react differently to prescribed medicines, or need special help to comply with doctors' orders.

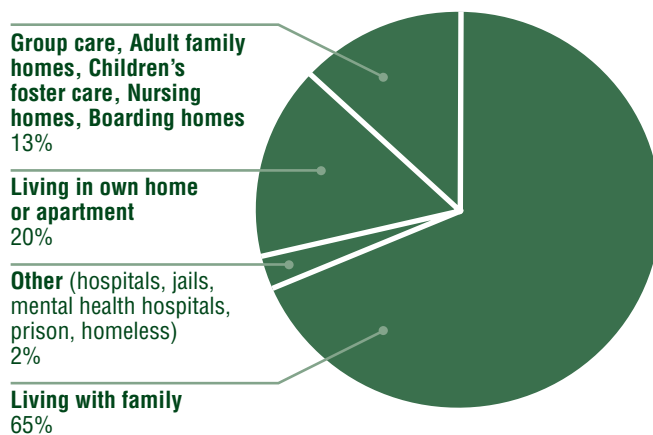
Coordinating these services and ensuring that people with developmental disabilities get what they need requires extra effort. To address one such challenge, the Developmental Disabilities Services is working with the Mental Health Division of DSHS to create better understanding of the needs of people with developmental disabilities, to improve communication between case managers and mental health practitioners, and to get needed services faster.

Community protection

Some people with developmental disabilities commit violent crimes such as rape or arson, although the incidence of criminal behavior is no higher among people with developmental disabilities than among the general population. But caring for people with developmental disabilities who commit crimes presents special challenges. Some are not competent to stand trial, and those who are convicted and serve prison terms eventually return to the community. The Community Protection Program provides 24-hour supervision and treatment for these offenders, who usually live in their own apartments or rented houses.

This population presents unique challenges because they are both dangerous and vulnerable.

Most people with developmental disabilities live with their families or in their own home or apartment



Aacres Landing, Inc.; AACRES Allvest, LLC

Services: Rehabilitative and transitional services for individuals with developmental disabilities with an emphasis on community living.

Communities served: Primarily Pierce County Tacoma, one-third of client population is served in Vancouver, Seattle, and Spokane.

DSHS clients: 178

Private as well as public clients? Yes

Year formed: AACRES Landing 1974; AACRES Allvest, LLC, 1999

Employees: 425

Payroll per year: \$9.5 million

Total annual budget: \$13 million

DSHS or federal funding brought into the community through contract with DSHS: \$13 million

The federal government has strict rules that govern the programs that they help pay for. These rules require specific, high standards of care in institutions. Federal rules also require that people who are eligible for institutional care or are in the Community Alternatives Program be served within 90 days of the time their need for services is established.

The federal Department of Justice protects the civil and human rights of people with developmental disabilities, and regularly monitors state institutions and other programs to ensure that those rights are respected, and to take action when they are not.

Challenges for people with developmental disabilities and those who help them

Creating a culture of inclusion

Our society has a long history of excluding and rejecting people with developmental disabilities. This tradition is being challenged by the movement towards community living, by universal access to public education, and by the growing activism of people with developmental disabilities and their advocates. But we have a lot of work yet to do if we are to create truly inclusive communities in which every human being is valued for their unique gifts rather than labeled and categorized in terms of their disability.

Many are victims of abuse and exploitation as a result of their disability. At the same time, community members may not recognize that they are dangerous, because their disabilities may make them seem harmless.

The federal government and people with developmental disabilities

Most adults with developmental disabilities receive some income support from the federal government. Depending upon family income, some children may also receive income support. Most

also are eligible for Medicaid, which pays for medical care and some help with tasks of daily living. The federal government also pays for 50 percent of the cost of caring for people who live in institutions. To help people who would have lived in institutions in the past, but now choose to live in community settings, the federal government created Home and Community Based Services Waivers. Washington's waiver is called the Community Alternatives Program (CAP). This program uses federal funds to pay for half the cost of services that allow people to live in community settings.

Serving more people with higher expectations

People with developmental disabilities want to choose how and where they live, and what they do with their lives. And in the last 25 years, our society has arrived at a strong consensus that people ought to be able to make those choices.

To help people live as independently as possible in the community, we have stitched together a system of government funding and services, public education, private and non-profit care providers, and family support. At the same time, we have kept open the institutions for the 1,100 people who continue to reside in them. Today, government is expected to provide and coordinate access to a much more complex array of services and supports than ever before.

But in some instances, government is still unable to provide what people want most: genuine self-determination, meaningful choices, and quick service. Inadequate case management staffing, lack of community-based providers, and limited funding all inhibit people's access to the services they need in order to build the lives they want. Shortages of caregivers are also a problem for many people; some caregivers are paid as little as \$7.22 an hour, and good ones are hard to find and keep.

Providing choice, protecting consumers

Today, many people with developmental disabilities and their families hire and fire their own care providers, choose which services or supports they will buy, or which adult family home or other facility they will live in. These supports are paid for by government, but chosen by people with developmental disabilities and/or their families.

This trend towards greater client choice is supported by state and federal policy. There is discussion under way about how to extend this concept, perhaps by giving people who qualify for services an annual, budgeted amount, and letting them spend it as they wish to buy the services they want.

Consumer choice and decision making dramatically change the role of state government. In addition to being responsible for providing high quality care in institutions, state government is now responsible for assuring the quality of care chosen by others and provided by others. This consumer protection function is complex and difficult. It raises new questions about how to assure the quality of services, how to protect people from neglect, abuse and fraud, and how to apportion responsibility and legal liability when they occur.

The trend towards client-directed services also poses special problems for people with developmental disabilities who may need special help to make good choices about their care.

Managing a complex web of partnerships

When the state's obligation to people with developmental disabilities was limited to managing large state institutions in which many of them spent their entire lives, the challenge faced by government wasn't easy, but it was certainly simpler. The partners involved in running institutions were few: state agency employees, the state legislature, and people with developmental disabilities and their families.

No one wants to go back to that system, and hardly anyone doubts that the movement towards authentic self-determination and community living is the right path to follow. But there are many more partners in this new system: people with developmental disabilities; their families; a wide array of advocacy organizations and attorneys; county, state, tribal and federal government agencies; the U.S. Congress and the state legislature; private, individual and nonprofit caregivers and agencies; the courts; state employee unions; volunteers; human rights organizations and taxpayers. Managing this complex set of partnerships is a daunting challenge.

In this environment, it is also a complex challenge to make sound public policy that serves the best interests of people with developmental disabilities and accurately represents the values of Washington taxpayers.